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(2013) It's more than just physical therapy: reported utilization of physiotherapy services for adults with neuromuscular disorders attending a specialist centre. *Disability and Rehabilitation*, 35 (4). pp. 282-290. ISSN 0963-8288

Downloaded from: <https://e-space.mmu.ac.uk/610429/>

Version: Accepted Version

Publisher: Taylor & Francis

DOI: <https://doi.org/10.3109/09638288.2012.691940>

Please cite the published version

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Title

It's more than just physical therapy: reported utilisation of physiotherapy services for adults with neuromuscular disorders attending a specialist Centre.

Abstract

Purpose

The purpose of this study is to evaluate service users' perceptions of their utilisation of the physiotherapy service at a specialist Neuromuscular Centre and to identify their reasons for and barriers to attending.

Method

A prospective survey design, consisting of a 13 item questionnaire was completed by 104 registered users of a physiotherapy service at a Neuromuscular Centre in northwest England. Descriptive statistics was employed to analyse data from Likert style questions and thematic analysis conducted on responses to open ended questions.

Results

Over 79% of respondents were satisfied with the frequency and duration of their treatment. Respondents attended physiotherapy to obtain physical therapy, for general wellbeing and to access specialised resources. Barriers to attendance included work commitments, travel cost and time, and lack of Centre resources. Clients attending physiotherapy valued the specialist service including advice from therapists, perceived benefit from social interaction with other clients and physical therapy.

Conclusion

Adults with neuromuscular disorders identified psychosocial as well as physical benefits from attending physiotherapy at the Neuromuscular Centre. The findings highlight the importance of service users' views in service provision and suggest that a collaborative commitment to patient management could be advantageous when developing physiotherapy services.

Keywords: Disability, neuromuscular disorders, physical therapy, patient satisfaction, physiotherapy, neuromuscular

Introduction

Muscular dystrophy and related neuromuscular disorders (NMD) are a heterogeneous group of conditions, typically producing chronic muscle weakness which may precipitate reduced function and participation [1-4]. Common forms of NMD include myotonic, facioscapulohumeral, Becker and Duchenne dystrophies, Charcot–Marie–Tooth disease and spinal muscular atrophy. There are over 40,000 people in the USA and 70,000 in Western Europe with severe symptoms related to this condition [4]. In the UK, there are approximately 60,000 people with varying manifestations of NMD [5], with an occurrence of 37 per 100 000 with inherited muscle disease in Northern England [6]. A review of services in the UK for adults with NMD has found that there is an inconsistency in the availability of specialist input for these conditions [5,7].

Whilst physiotherapy cannot reverse the disease process, targeted exercises may delay or prevent secondary conditions such as obesity and osteoporosis, and improve general fitness [8,9]. It has also been suggested that development of deformities secondary to some NMD can be delayed with physical intervention [10]. Exercises may also help improve sleepiness, a common symptom of NMD [11]. Importantly, physical exercise has been shown to cause no harm to people with NMD [12,13], and has shown to be of benefit to mental health and general well being in the general population [14,15]. However, access to physiotherapy appears restricted for adults with NMD, with some individuals unable to receive input from physiotherapists who have expertise of their condition, or gain regular ongoing treatment to manage their situation [7,16,17].

The Neuromuscular Centre (NMC) is a voluntary sector rehabilitation centre which provides specialist and holistic care for people with NMD in North West England and Wales. Services offered include physiotherapy, hydrotherapy, psychosocial support, advice and education on all aspects of NMD. Of the 360 registered users, 190 clients accessed physiotherapy in the year 2009-10 [18], although it is estimated that only 150 attend physiotherapy on a regular basis. It has been suggested that physiotherapy services are under or over used by people with NMD [3]. Whilst it has been argued that a course of 6 to 8 weeks of physiotherapy was appropriate for people with NMD [3], this fails to consider the user's perception of their needs and the variability of symptoms inherent to NMD. Access to specialist physiotherapy has been highlighted as one of the main perceived benefits of attendance at the NMC [16]. However, there has not been any formal evaluation of this service nor its utilisation by adults with NMD. Furthermore, there is a scarcity of literature investigating NMD client's views of specialist services such as that offered at the NMC. Therefore, this study aims to describe and explore the utilisation of physiotherapy at the NMC and gain some insight into service users' perceptions of this service provision, in order to share practice and inform debate.

Objectives

To describe patterns of utilisation of physiotherapy at a NMC

To determine the reasons for utilisation of physiotherapy at a NMC.

To identify any barriers to utilisation of the physiotherapy service

Methods

Participants

All adults who attended the NMC for physiotherapy in a 2 month period between July and September 2010 were invited to participate.

Design

This study design was a prospective, cross sectional survey of adult users of the NMC physiotherapy service.

Physiotherapy Provision

Physiotherapy at the Centre offers ongoing, specialised treatment programmes based on clients' individual needs. Treatments include: passive stretching and mobilisation of the muscle and joints, exercise for core stability and balance, gait re-education, and personal home exercise programmes. Intermittent compression with the aid of Flotron boots is available to relieve lower limb swelling and specialist equipment such as hoists, standing frames and tilt table are used to stand or to mobilise clients who are unable to stand or mobilise independently. Swiss balls and a hydrotherapy pool are regularly used as part of the exercise regimes. Pain relieving modalities such as acupuncture, electrotherapy and massage techniques are also employed.

Ethics

Ethical approval was gained from the Manchester Metropolitan University, Department of Exercise and Sports Science academic Ethics Committee. As this is a service evaluation of a registered voluntary organisation, NHS ethical approval was not required.

Questionnaire

A 13 item questionnaire was developed and refined following a pilot study of 9 subjects who attended the NMC for physiotherapy. Items recorded demographic details including the type of NMD, time since diagnosis, age and gender. Likert style items were used to investigate the severity of the respondent's condition, the frequency and duration of their attendance at physiotherapy and whether they thought this was appropriate. Open questions invited respondents to record their reasons for attending physiotherapy at the NMC and any barriers to attendance. This was in order to gain more insight and understanding of the utilisation of the physiotherapy department from the viewpoint of respondents [19].

All clients aged 18 or over who attended for physiotherapy between July and October 2010 had the opportunity to be involved in this research. Questionnaires with accompanying information sheets were offered to clients when they attended for physiotherapy treatment, of which 125 clients chose to take and 8 declined.

Participants chose to complete the questionnaire at home and return via stamped addressed envelopes or when attending the Centre. By the closing date specified, 104 participants (78%) had returned their completed questionnaires. Participant anonymity was ensured; participants being requested not to include their name on the questionnaire, but to write a unique code which was identifiable only to them should they wish to withdraw their information. Participants were advised that an electronic format of the questionnaire was available upon request.

Analysis

All returned questionnaires were analysed. Descriptive statistics were used to summarise demographic information and responses to Likert questions.

Open questions were initially subjected to thematic analysis. As a starting point, participants' responses for each question were written down by the researcher, with a separate piece of paper for each question. The responses were then read and reread to gain an insight in to the overall picture that was being presented [20]. Basic codes were subsequently identified based on recurring words or phrases that originated from the responses. Codes that appeared related were then arranged together to form categories. Finally, similar categories were grouped together under an over-arching theme which best described the key concepts that were being made [21] (see figure 1). Accuracy of the findings was confirmed by a second independent researcher who had examined the data and corroborated the categories and themes identified; thus enhancing the credibility of the results.

Content analysis was used to ascertain the frequency of responses that related to each theme identified. [19]. Individual quotes from participants, which supported these themes and illuminated significant comments, were added [19].

Figure 1

Figure 1 to be inserted here

Results

One hundred and four participants (34 females) with a variety of neuromuscular conditions (see table 1), completed and returned the questionnaire. There were 2 questions with non-responses: length of attendance (2 non-respondents) and sufficiency of treatment duration (1 non-respondent). Overall percentage responses for these questions were therefore calculated from a total of 102 and 103 participants respectively (see below and table 2).

Participants had a mean age of 46.42 years (SD 15.07; range 18-81; men: 46.4, SD 16.3yrs; women 46.5, SD 12.4yrs), with a mean time since diagnosis of 21.45 years (SD 12.82; range:0.5-58; men: 20.74, SD 12.55; range 0.5-53; women 22.91, SD 13.44; range 3-58).

Fifty-one percent (n=53) of participants reported completing some daily activities with assistance, 16% (n=17) could complete all tasks unaided whilst 23% (n=24) required assistance for tasks and 10% (n=10) could not complete most daily tasks. (See table 1 for detailed characteristics and functional level for each neuromuscular condition).

Table 1 HERE

Table 2 HERE

As can be seen from table 2 the majority of participants had been attending physiotherapy for several years. From 103 respondents, 98% (n=101) reported that their treatment session length was sufficient. Similarly, the majority reported that they considered the frequency of attendance to be sufficient, 79% (n=82), whilst 20% (n=21) felt they attended too little. One participant (1%) felt that the frequency of physiotherapy at the NMC was too much.

Of the 104 respondents, 88 % (n=92) attended at least once a fortnight, 9% (n=9) once a month and 3% (n=3) less than once a month. Of the 92 participants who attended a least once a fortnight, 83% (n=76) were satisfied with this frequency of attendance, 16% (n=15) reported that this was too little and 1% (n=1) reported that it was too much. Of the 9 participants who attended once a month, 56% (n=5) were

satisfied and 44% (n=4) reported that this was too little, and of the 3 participants who attended less than once a month 33% (n=1) was satisfied and 67% (n=2) reported that the frequency was too little. The frequency of attendance was reported to be decided collaboratively by the physiotherapist and the patient by 59% (n=61) of participants, by the physiotherapist alone 26% (n=27), by the patient alone 12% (n=13) or by other factors 3% (n=3) including the ability to access to transport and work commitments.

Reasons for attending for physiotherapy

There appeared to be 3 themes which arose from analysis of the data as to why participants attended the physiotherapy department: to obtain physical therapy, for general wellbeing and to access specialised resources, including staff who they perceived as experts in the condition.

Physical Therapy

Fifty-six participants (54%) identified receiving physical input and the prescription of exercises to stretch and strengthen muscles as one of the main reasons why they attended for treatment. They particularly felt that it helped them to keep mobile and remain independent for as long as possible.

Comments from participants as to the physical benefits included:

“The physio helps keep my movementkeeps what strength I have in my muscles active which enables movement”

“ the role of the physiotherapist is to help me maintain my mobility to help me maintain the continued functionality of muscles affected by my condition which

otherwise would lose strength and cease to work effectively. Basically they help me to continue walking and to live independently”

It was also acknowledged that attending physiotherapy helped to motivate and encourage some participants to be more proactive in carrying out their exercises and helping themselves.

Comments from participants included:

“I feel as if I’m doing something to help myself”.

“Left to my own devices, I would probably do nothing”

To get “pain relief” or “cope better with pain” was identified as another physical benefit for attending physiotherapy at the NMC. However, this was clearly not a universal finding as one participant stated that they had sought treatment elsewhere to help relieve pain.

“I’ve been elsewhere between physio sessions at the NMC because of pain and discomfort that I felt I couldn’t cope with until my next session. I have also attended other physio sessions because I felt my issue was too specific for the NMC”.

Additional physical benefits recognised by participants for attending physiotherapy included, maintaining their physical status, general fitness and health, to prevent contractures and chest infections and to assess and monitor and slow down disease progression.

General well being

Forty-three (41%) participants identified psychosocial benefits which improved their general wellbeing as a reason why they attended for physiotherapy. The department

appeared to offer a positive, relaxing environment, which was seen by some participants as friendly, comfortable and fun.

This can be seen in comments from some participants:

“It has a really nice atmosphere with everyone else there having physio with similar issues which is motivational”

“...it stimulates mental and physical wellbeing”

“It makes me feel good”.

Attending physiotherapy was seen for some as a meeting place for social interaction and “*entertainment*”. It seemed that accessing physiotherapy at the NMC allowed participants to talk over problems and share their experiences which appeared to help them cope with their situation. Some participants identified that attending physiotherapy gave them confidence about their disability and helped to improve their quality of life.

Some of the psychosocial benefits gained from attending physiotherapy can be seen in the following participants’ comments:

“Having contact with other users of NMC who I would not normally see and who have MD, able to share experience of living with MD”

“The NMC is a place where you feel understood - A round peg in a round hole”.

“The perfect antidote to depression”

Access specialised resources

Thirty-two participants (31%) identified access to specialised resources and specialist staff who knew about their condition as another reason to attend the physiotherapy department. Participants reported that the physiotherapy department offered specialised equipment such as aids to help with daily living, a standing frame and a hydrotherapy pool. They also identified that accessing physiotherapy allowed them to gain information about support and equipment that was available, and provided them with the opportunity to be educated on available treatments and up to date research about NMD. Some participants saw staff as experts with regards to the condition, who were supportive and understanding of their situation. They also felt that staff tailored the treatment to their individual needs.

This can be seen in the participants following comments:

“..NMC physiotherapists are specialised and highly skilled in the appropriate treatments needed for this type of condition”

“The standard of physiotherapy at the NMC is of a very high standard, delivered by physios who generally care about their clients.”

“The physios....their friendly can - do atmosphere is life enhancing really. It's a wonderful place”

Ten participants (10%) reported that they accessed physiotherapy at the Centre because it was the only place that physiotherapy was made available for them as they were unable to access any from the NHS, and the NMC was a place where they could receive regular treatment.

As one participant stated:

“....I dread to think how different my life would be if I hadn't had the treatment and support I have received from all aspects of the services provided by the NMC”

Barriers to attending physiotherapy.

Although only 20% of participants (n=21) felt that they received too little treatment, 27% (n=28) identified a number of barriers to attending physiotherapy, of which two main themes arose: barriers to attending the Centre and benefits that participants thought they would gain from attending more often.

Barriers to attending the physiotherapy at the NMC

There appeared to be 3 sub themes identified by participants as barriers to attending physiotherapy at the NMC: personal, the Centre itself and economics.

Personal

Twenty- four out of 28 participants (86%) identified personal factors as barriers to attending physiotherapy. These included issues such as work or study commitments, looking after their children and the need to attend for hospital appointments. Other reasons identified as affecting their ability to attend were the state of their condition and tiredness.

Comments by participants of attendance included:

“Work constraints mean I attend once a week. Ideally I would like to attend twice a week”

“I have a young son who I have to make sure is cared for”

“This is about all I can cope with”.

The Centre

Eight of the 28 participants (29%) stated that barriers arose from the Centre itself.

Reasons highlighted were due to limited funding which lead to a lack of physiotherapy resources. In particular participants identified that there were too many clients attending and a shortage of staff which affected the availability of more appointments and the time available for treatment. One other factor identified as being a barrier to treatment was if the hydrotherapy pool was closed.

Some comments from participants included:

“I think it is a fair amount of time especially due to the number of patients currently receiving treatment at the NMC. However, able bodied people who attend a gym would generally go more frequently then this so it is often frustrating that physiotherapy/exercise time is limited through no fault of my own”.

“Too many clients and not enough physios”

“NMC is worked to death and overstretched, no support from NHS for people with long term degenerative disability. Don’t bother us we can’t fix you attitude, more interested in targets”

Economics

Twenty-six out of the 28 participants (93%) also identified economic factors as affecting their attendance for treatment. This included the distance to travel to the Centre for treatment and the lack of access to treatment nearer to home. This was highlighted as being costly to the participants both in time and money. Some participants identified the need for their carer to be available to accompany them to

the Centre or a driver to transport them for treatment. Incurring this extra cost seemed to provide an additional financial burden.

These barriers were acknowledged by participants in comments such as:

“I would like physiotherapy on a weekly basis, unfortunately the travelling time and cost involved doesn’t make this possible”

“Getting transport here as I don’t drive so I rely on a paid carer to get here”

“I live in ‘Location X’ which is about a 2 hour drive. I would attend weekly if it wasn’t for the travelling”

Potential benefits from greater attendance

Ten participants out of 28 (36%) identified benefits that they thought they would gain from attending more often. These were physical benefits as a result of more stretching, which they reported would give increased flexibility and reduce pain and stiffness. Increased psychological benefits were also reported to be likely to occur.

“I feel that once a week is more appropriate as I feel much more supple afterwards and that after two weeks I am feeling much... less flexible”

“two sessions in the week would make more comfortable throughout the week as currently with one session I am less comfortable at the end of the week”

“more beneficial physically and mentally to attend more often ..”

DISCUSSION

Patterns of utilisation

Over 79% of participants reported that their treatment frequency and duration was appropriate for their needs, suggesting that the majority were satisfied. However, 20% (n=21) felt that they had too few treatment appointments and 2% (n=2) felt that the treatment session duration was insufficient. Only 1 participant (1%) felt that the frequency of attendance was too much. Most respondents had been attending physiotherapy for several years.

The majority of participants, 92 attended physiotherapy at least once a fortnight: of which 82% (n=76) were satisfied with this frequency. Even so, 15 out of the 21 participants (71%) who were not satisfied with their frequency of attendance were also receiving treatment at least once a fortnight. This therefore highlights the variability in clients' expectations of the optimal frequency of treatment.

The extent of physiotherapy management for people with NMD was challenged by Cup et al [3], who claimed that a number of these patients received unnecessarily prolonged episodes of treatment. They suggested 6 to 8 sessions were more appropriate, with an exercise regime for the patient to continue on their own.

However, as seen in this study, NMD encompasses a wide range of ability. With such variation in physical needs, any standardisation of treatment frequency for this patient group could be argued to be over simplistic, and would not lead to patient centred care which has been identified as an important facet of rehabilitation [22]. Even so, it could be said that encouraging the need for regular physiotherapy by providing continual access to treatment, may lead to individuals becoming too dependent on specialist input and therefore less motivated to help themselves [23]. So, what would seem most beneficial is to foster an environment that facilitates clients to be more active participants in their own management. Therefore, rather than being reliant on continuous physiotherapy input, clients are motivated to share

the commitment to their physical wellbeing [23]. More time educating on home exercise programmes, collaborative goal setting between specialist physiotherapists and their clients and guidance on such issues as fatigue management could, when appropriate, endow clients with strategies to assist them to achieve this [8,24,25]. Nevertheless, the extent and progression of the condition, leading to differing client needs, will necessitate variability in intervention and hence frequency of attendance [26]. Therefore, access to specialist physiotherapy when needed and regular reviews where progression can be monitored will be required to support any collaborative partnership [27]

More research needs to be undertaken to explore the promotion of a shared responsibility for patient management between physiotherapy providers and NMD service users, and whether this could lead to more optimal utilisation of this specialist service.

Reasons for utilisation

One of the main reasons identified by participants for attending the physiotherapy department was for the physical benefits including the relief of pain. Pain has been recognised as a common symptom by people with NMD [11,28]; indeed in this study, pain seemed to be a concern for a number of participants. A number of pain relieving modalities are used at the NMC and these were acknowledged by some participants to have reduced their pain, however it was also reported that treatment for pain relief had to be sought elsewhere by others. The mechanism by which physiotherapy may relieve pain in people with NMD is not clear and therefore warrants further research to explore pain management in this client group. [11].

In this study, participants highlighted that attending the NMC for exercises helped them to remain mobile and independent for longer and improved their general fitness and health. Some participants identified that they felt encouraged and motivated to help themselves and to carry out exercises. Previous research has found that individuals with NMD take less physical exercise than healthy controls and perceive more barriers to being physically active [29]. This is a particular issue, as NMD is a progressive condition leading to weakness, and reduced physical ability [30, 31], which can result in secondary problems as a consequence of a sedentary lifestyle and lack of exercise [8,9]. Reduced physical exertion in individuals with NMD has also been found to increase fatigue and decrease the ability to function [31,32]. Conversely, physical exercise has been found to retain and improve the functional ability of individuals aging with physical impairments [8]. The findings of this study suggest that people with NMD want to participate in physical exercise and see the physiotherapy service as a mechanism to allow them to do this. The provision of this service may also improve symptoms of NMD, help to reduce fatigue and delay the deterioration in muscle strength, thus helping with the individuals' ability to physically function.

It was also clear that there were other advantages to attending physiotherapy as well as physical benefits. The department provided a supportive environment for some participants where clients could access information and advice about their condition. Socially, it was seen as a place to meet, and interact with others, and psychologically by providing assistance to each other to cope and manage problems that they encountered. This seemed to provide participants with encouragement and more self-assurance about their situation. It has been found that engaging with people in similar circumstances is more likely to provide an environment where individuals are

more compassionate and supportive of each other [16]. Whether it is having a similar physical condition that is important or a comparable life situation is not clear.

However, in this study, participants had a wide range of conditions which seems to suggest sharing similar problems, rather than diagnoses, is a unifying factor. Gaining more knowledge and awareness of NMD through education and advice could encourage clients to become more involved in managing their condition and therefore potentially more physically active [33,24]. Empowering individuals to become more self-determined in this way could also provide psychological support by helping to improve self-esteem and self-confidence [24]. More research is required to explore further how the department can be cultivated to facilitate health promotion and more active participation in management of one's own condition.

A further benefit to attending the NMC was access to specialised resources including hydrotherapy, and staff who understood their condition. Access to specialised equipment, including staff with expertise of the condition is restricted in the UK for some people with NMD [5]. Treatment under the supervision of physiotherapists who have expert knowledge of NMD and access to specialised equipment should be more advantageous, as patient progress can be regularly assessed and managed more effectively [13]. Although it is apparent that the physiotherapy service at the NMC is valued by clients, it is not clear which aspects of this service is most beneficial. This may mean that the service is offering specific components of therapy which have little or no benefit, or that all elements of attendance to physiotherapy are equally important and should be maintained. Therefore, future research should consider objective benefits alongside those perceived by the clients from their attendance at physiotherapy, to ensure a holistic approach to management.

Barriers to utilisation

Two of the main themes identified relating to barriers to attending physiotherapy, were work commitments and the distance to travel to the NMC. Variability in access to physical therapy has been identified for people with NMD in the UK [7,16]. This study confirms previous findings that some people with NMD have to travel large distances to gain access to specialised treatment [5]. The implications of this have been identified by participants in this study as costly in time and money. Fatigue is a common feature of NMD [32,34], the extra time and effort spent in travelling could intensify this symptom, negating any benefits from attending the NMC. The cost of travel in terms of petrol or the need to employ drivers or carers for longer provides an additional burden, especially as some individuals with NMD may be less prosperous due to reduced prospects of being employed [34-36].

Long term conditions incur the most expenditure to health services; in the UK they are recognised to take up “50% of GP appointments and 70% of inpatient hospital beds” [37]. Although people with NMD will account for only a small proportion of these figures, providing them with physical therapy to manage the condition and delay progression could help to reduce future medical costs and hence the total cost to society. However, lack of funding for physiotherapy was identified by participants as another perceived barrier to treatment. It was felt that this affected resources and limited the frequency of attendance for some. The NMC is financed by charity sponsorship and some self-funding. As in many third sector organisations, funding can fluctuate and so more sustainable revenue needs to be obtained to ensure survival of the physiotherapy service at the NMC. The NMC has undertaken to procure contracts with their local NHS primary care trusts; however it would seem that more long term commitment from the health service is needed. This appears

particularly pertinent as some participants acknowledged that the NMC was the only place they could access and have regular treatment.

Limitations

The findings of this study are limited as only one centre was utilised and therefore it is unclear if the results could be transferable to other environments. However, it is probable that some of the study findings can be viewed by individuals in comparable situations as reflective of their own circumstances [38].

A further limitation of this work is the sample utilised. Only clients attending the NMC were surveyed which may introduce a positive bias. It may be that those who choose not to attend the NMC do not value the physiotherapy service offered, or there may be unexplored barriers to them attending. Therefore, further research to investigate their non attendance needs to be undertaken.

The questionnaire design restricts the freedom and detail of responses and therefore reduces the richness of data that can be gained from participants. However, this design did allow a large number of patients to be surveyed. Future research, including interviews, could further delve into participants' responses and help provide a more in depth insight of their perceptions.

Conclusion

This study has outlined the utilisation of specialist physiotherapy services for adults with NMD and explored the reasons and barriers to attendance to treatment.

Participants were most commonly seen once every week or every two weeks and most had been attending the centre for more than 5 years. They highlighted several reasons for attending physiotherapy, namely physical therapy, general well being and

access to specialist resources. Barriers to attendance included work commitments and economic costs. Several participants needed to travel large distances due to the lack of access to physiotherapy treatment or the availability of a more local comparable service.

The findings suggest that clients attending physiotherapy at the NMC value the specialist service, and perceive benefit from social interaction with other clients and advice from therapists, in addition to physical therapy. These results indicate that although physiotherapy services can be provided for physical benefits alone [3], non physical aspects of treatment are also highly valued by clients.

This study adds to the debate about what constitutes the essential elements for service provision for adults with NMD. It is only through the consideration of clients' views when evaluating services for people with NMD, that specialist care can be developed to ensure that it is maximally beneficial for service users and not just perceived to be so by the service providers.

Even so, there is a need to ensure that treatment planning is realistic, economically viable and empowering for the individual. Therefore, what appears to be the challenge for the future is to determine what would constitute a balance between providing adults with NMD necessary access to specialist physiotherapy intervention without facilitating dependency, by encouraging reliance on regular professional input. Findings from this study suggest that developing a collaborative partnership between physiotherapy providers and NMD service users to share the commitment to patient management could help in achieving this.

Acknowledgements

The authors would like to thank participants and staff at the NMC who supported and took part in this research.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

References

- [1] Mukherjee M, Mittal B. Muscular Dystrophies. Indian Journal of Paediatrics 2004;71:161-168.
- [2] Brown SC, Jimenez-Mallebera C. Biochemical and molecular basis of muscle disease. In Karpatis G, Hilton-Jones D, Bushby K, Griggs RC, editors. Disorders of voluntary muscle. 8th ed. Cambridge: Cambridge University Press; 2010. p 37–80
- [3] Cup EH, Pieterse AJ, Knuijt S, Hendricks HT, Van Engelen BG, Oostendorp RA, Van der Wilt G. Referral of patients with neuromuscular disease to occupational therapy, physical therapy and speech therapy: Usual practice versus multidisciplinary advice. Disability and Rehabilitation 2007;29:717-726.
- [4] Emery AE. Muscular Dystrophy. Third ed. Oxford: Oxford University Press 2008. p 1-3
- [5] All Party Parliamentary group for Muscular Dystrophy. Access to Specialist Neuromuscular Care: The Walton Report. London: Muscular Dystrophy Campaign; 2009:7-11
- [6] Norwood FL, Harling C, Chinnery PF, Eagle M, Bushby K, Straub V. Prevalence of genetic muscle disease in Northern England: in-depth analysis of a muscle clinic population. Brain 2009;132: 3175-3186
- [7] Hill ME, Phillips MF. Service provision for adults with long-term disability: A review of services for adults with chronic neuromuscular conditions in the United Kingdom. Neuromuscular Disorders. 2006;16:107-112.
- [8] Rimmer JH. Exercise and physical activity in persons aging with a physical disability. Physical Medicine and Rehabilitation Clinics of North America. 2005; 16:41-56.

- [9] Ravestloot C, Seekins T, Young Q-R. Health promotion for people with chronic illness and physical disabilities: the connection between health psychology and disability prevention. *Clinical Psychology and Psychotherapy* 1998; 5:76-85.
- [10] Dubowitz V. Deformities in Duchenne dystrophy. *Neuromuscular Disorders* . 2010; 20:4:282.
- [11] Kierkegaard M, Harms - Ringdahl K, Holmqvist LW., Tollbäck A. Perceived functioning and disability in adults with myotonic dystrophy type 1: a survey according to the international classification of functioning, disability and health. *Journal of Rehabilitation Medicine* 2009; 41:7:512-520.
- [12] Voet NBM, van der Kooi EL, Riphagen II, Lindeman E, van Engelen BGM, Geurts ACH. Strength training and aerobic exercise training for muscle disease (Review). *Cochrane Database of Systematic Reviews* 2010; 1. Art. No.: CD003907. DOI: 10.1002/14651858.CD003907.pub3.
- [13] van der Kooi EL, Lindeman E, Riphagen I. Strength training and aerobic exercise training for muscle disease (Review). *Cochrane Database of Systematic Reviews* 2005; 1. Art. No.: CD003907. DOI: 10.1002/14651858.CD003907.pub2.
- [14] Busch AJ, Barber KA, Overend TJ, Peloso PMJ, Schachter CL. Exercise for treating fibromyalgia syndrome. *Cochrane Database of Systematic Reviews* 2007; Issue 4. Art. No.: CD003786. DOI: 10.1002/14651858.CD003786.pub2.
- [15] Mead GE, Morley W, Campbell P, Greig CA, McMurdo M, Lawlor DA. Exercise for depression. *Cochrane Database of Systematic Reviews* 2009; Issue 3. Art. No.: CD004366. DOI: 10.1002/14651858.CD004366.pub4.
- [16] Hartley SE, Goodwin PC, Goldbart J. Experiences of attendance at a neuromuscular centre: perceptions of adults with neuromuscular disorders. *Disability and Rehabilitation* 2011;33:12:1022-1032
- [17] Muscular Dystrophy Campaign. Building on the foundations: the need for a specialist neuromuscular service across England. London: Muscular Dystrophy Campaign; 2007:2.
- [18] NeuroMuscular Centre. Social accounts and annual report and financial statements. Winsford: NMC; 2009–10:5
- [19] O' Cathain A, Thomas KJ. "Any other comments?" Open questions on questionnaires – a bane or a bonus to research? *BMC Medical Research Methodology* 2004; 4:25:1-7. <http://www.biomedcentral.com/1471-2288/4/25>. Accessed 2011 Jan 11
- [20] Hsieh H, Shannon SE. Three approaches to qualitative content analysis. *Qualitative Health Research* 2005;15:1277-1288.

- [21] Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006; 3:2:77-101.
- [22] Cott CJ. Client-centred rehabilitation: what is it and how do we measure it? *Physiotherapy* 2008;94:2:89-90
- [23] Wilson PM, Mayor V. Long-term conditions. 2: supporting and enabling self-care. *British Journal of Community Nursing* 2006;11:1:6-10
- [24] Davies NJ. Improving self-management for patients with long-term conditions. *Nursing Standard* 2010;24:25:49-56
- [25] Dawes H, Korpershoek N, Freebody J, Elsworth C, van Tintelen N, Wade DT, Izadi H, Jones DH. A pilot randomised controlled trial of a home-based exercise programme aimed at improving endurance and function in adults with neuromuscular disorders. *Journal of Neurology, Neurosurgery and Psychiatry* 2006;77:959-962
- [26] Pomeroy VM. Facilitating independence, motivation and motor learning. *Physiotherapy* 2007;93:2: 87-88
- [27] Kielmann T, Huby G, Powell A, Sheikh A, Price D, Williams S, Pinnock, H. From support to boundary: A qualitative study of the border between self-care and professional care. *Patient Education and Counseling* 2010; 79:1: 55-61
- [28] Jensen MP, Abresch RT, Carter GT. The reliability and validity of a self-report version of the FIM instrument in persons with neuromuscular disease and chronic pain. *Archives of Physical Medicine and Rehabilitation* 2005; 86:116-122.
- [29] Phillips M, Flemming N, Tsintzas K. An exploratory study of physical activity and perceived barriers to exercise in ambulant people with neuromuscular disease compared with unaffected controls. *Clinical Rehabilitation* 2009;23:746-755.
- [30] Boström K, Ahlström G. Living with a hereditary disease: Persons with muscular dystrophy and their next of kin. *American Journal of Medical Genetics* 2005;136A:17-24.
- [31] McDonald CM. Physical Activity, Health Impairments, and Disability in Neuromuscular Disease. *American Journal of Physical Medicine & Rehabilitation* 2002; 81:108-120.
- [32] Kalkman J, Schillings ML, Zwarts MJ, van Engelen BG, Bleijenberg G. The development of a model of fatigue in neuromuscular disorders: A longitudinal study. *Journal of Psychosomatic Research* 2007; 62:5: 571-579.

- [33] Department of Health. The Expert Patients Programme. London: The Stationary Office, 2007.
- [34] Minis M.-AH, Kalkman JS, Akkermans R et al., Employment status of patients with neuromuscular diseases in relation to personal factors, fatigue and health status: A secondary analysis. *Journal of Rehabilitation Medicine* 2010; 42:1: 60-65.
- [35] Fowler WM, Abresch RT, Koch TR, Brewer ML, Bowden RK, Wanlass RL. Employment profiles in neuromuscular diseases. *American Journal of Physical Medicine and Rehabilitation* 1997; 76:26-37
- [36] Minis M.-A, Heerkens Y, Engels J, Oostendorp R, van Engelen B. Classification of employment factors according to the International Classification of Functioning, Disability and Health in patients with neuromuscular diseases: A systematic review. *Disability and Rehabilitation* 2009; 31:26:2150-2163.
- [37] Department of Health. Ten things you need to know about long term conditions. Department of Health 2011.
<http://www.dh.gov.uk/en/Healthcare/Longtermconditions/tenthingsyouneedtoknow/index.htm>. Accessed 2011 Feb 15
- [38] Stake RE. The art of case study research. London: Sage Publications; 1995. p 8